

## Responding With Families to Developmental Concerns: Parents Sharing About Special Services

Katie: Well, our journey to get special services started when our son was six months old. And prior to that, I knew that he had some vision issues, and he had crossed eyes, and I knew that his milestones weren't coming as quickly as I thought they should. And he was our second. He had some feeding issues and some jerky movements, and so all of that added up to something. We were seen by a physical therapist here in Seattle and occupational therapist as well, who evaluated our son and found that he was grossly delayed with his large motor skills at that age. Now, that's pretty young to get that designation as grossly behind, but it also affirmed that I knew that there was something different about the way he was developing.

Katie: And then from there, at the age of 7 months old, he started here at the University of Washington at the Haring Center. They have what's called the Experimental Education Unit (EEU). And our son was admitted into their Infant and Toddler Program and started with playgroups there. From day one when we started there, I can vividly remember going into the infant playgroup, and Teacher Carolyn and Teacher Kristy, who is a physical therapist, both were there for the playgroup, and they just embraced us, and they wanted to know about Jack, and they celebrated us having a son and an infant, and they just celebrated Jack. And I felt like I was home, and then I remember some of the younger staff members came in to meet us and introduce themselves and welcome us. And I just remember thinking, "Gosh, there's all these wonderful, happy people working here."

Katie: And it was also overwhelming, because I was taking the first step to get services for my 7-month-old. And we did not have a diagnosis at that point, and we did not have one for another, you know, 16 months or so. So, in those early, early months at the EEU, the staff just supported us in the journey through every test that we had, and they wanted to know the results. But they also—his diagnosis wasn't what was meaningful there. What was meaningful in his early services was that he was making progress and that he was happy and that we felt supported, and we knew that we had, you know, the right supports in place.

Paige: A little bit about our journey. We found out about halfway through my pregnancy, just randomly, that Eli had Down syndrome. And then, you know, we didn't know much about it, and we didn't know much about what life would be like. But we contacted our early intervention center and got everything in order so that right after he was born, we quickly had an evaluation and started services. So, he had his first physical therapy appointment in our house when he was two weeks old. Yeah. And I sort of thought, "Oh, it's going to be a total joke, because what can you do with a 2-week-old kid, you know, that I couldn't figure out?" But right away, just that support, having someone there, having small things to, you know, think about and do was super helpful.

Probably like a lot of moms, you know, found, like, a friend of a friend of a friend who had a friend who had a boy with Down syndrome. And I started by I met this lady and her little guy at the zoo. And talked to her, and she gave me some good tips. And so, I signed up for a couple online groups and found *Kindering*. So, we started there because it was our—the one in our area. And we had great support, great care. And then as we started to look ahead, my oldest son was in an elementary school, and we just knew that we weren't in the community we wanted to be in for our family.

I guess some of the things we love about the EEU, all of his teachers and paras and therapists are such a strong team, and so they all know what he's working on. They all support his goals. Yeah, they

talk with each other. They're all learning, you know, how to use this new device with us. They've come to his private therapy sessions. I mean, it's a pretty phenomenal place where they really take on everything that Eli has. Probably the best part, though, is that they have super high expectations for him, which I would say is probably one thing that you don't always find in the world right away. And they just do. Like I just got an email from his teacher, saying, "He's saying 'no' a lot. Is he saying 'no' at home?" I love that. They're going to treat him like everybody else. He's there to learn, he's smart, he's capable. And it feels really good to have him in a place like that.

Dave: Lenox, when she was 2, 2 1/2, was pointing, would mumble, or would get in very excited and be like [mumbles] and you couldn't understand anything. She could say mommy, daddy, or dada, and kind of her brothers' names, Jet and Sully. But only we could understand what they were. And then when we started with *Kids Talk*, from the very first day, we realized the reason she wasn't expanding her vocabulary is because we weren't—she didn't have to. There was no need to expand because her brothers would finish her sentences. We would get everything for her. And so we learned how to play. And I went in thinking, "This is not—How can this work? It's playtime." I play all the time with her. But the strategies that were taught, and taught in a way that they made sense.

Dave: So, for the first day, my job was just to not speak so much. Let her for 15 minutes play with Play-Doh and dolls and kind of stay out of it and listen to what she had to say. Which wasn't very much the first day. But the second day, when she's playing with the exact same toys, she might have a question. And then they taught me how to prompt her with, "What do you need?" Or, "Do you want the red one or the blue one?" So, we noticed very soon after *Kids Talk* began that her vocabulary was getting clearer. She was enunciating words. Like "mummy" was becoming "mommy," and "dada" was becoming "daddy." And just by repetition. And now it's amazing. Within 8 months, she went from no words, or a basic word, to three or four words in a row: "Mommy, can I have... a grape." We never thought that would happen.

Katie: So, the differences that special services have made for my family, and particularly our child Jack with special needs, is that the EEU, where Jack is, both of our typically developing kids have been able to go there as well. So, our eldest child is 7, our son Jack who has special needs is 5, and our baby is 2. And so half the kids at the EEU have special needs, and then half the kids are typical peers who are peer models for these kids with special needs. So, my eldest daughter, who is in second grade, spent two years in their preschool program. And she really understands kids of all needs and all levels and has compassion that I'm so grateful for. And I think it's a huge gift. And I think that that extends into every area of her life forever. And to have those experiences early, where you're really developing your sense of self and who you are, that's one huge way that that type of structure and type of school has, you know, had an effect on our family.

Katie: And then our son, Jack, has flourished. When he started there, he wasn't even crawling, and we didn't know when and if he would walk, because a lot of the kids that have genetic abnormalities such as his walk so later in life and talked so much later. But, you know, he's running, he's climbing, he's playing. His gross motor skills have come so far. His feeding skills, hard for him to feed himself. As well as his confidence. And I'd say the number one way that having these special services has impacted Jack is that Jack is Jack, and everyone at that school loves him for who he is. And we've been there for five and a half years, and now every morning when we get there, he takes one of the wagons, and our 2-year-old climbs in, and he pulls her around school, and we do this lap around the

outside of the school, through the hallways, and everyone's, "Good morning, Jack. How are you, Jack?" And I just see this little boy. I just see a little boy who's just happy and loved.